

COMMUNICATING TOGETHER

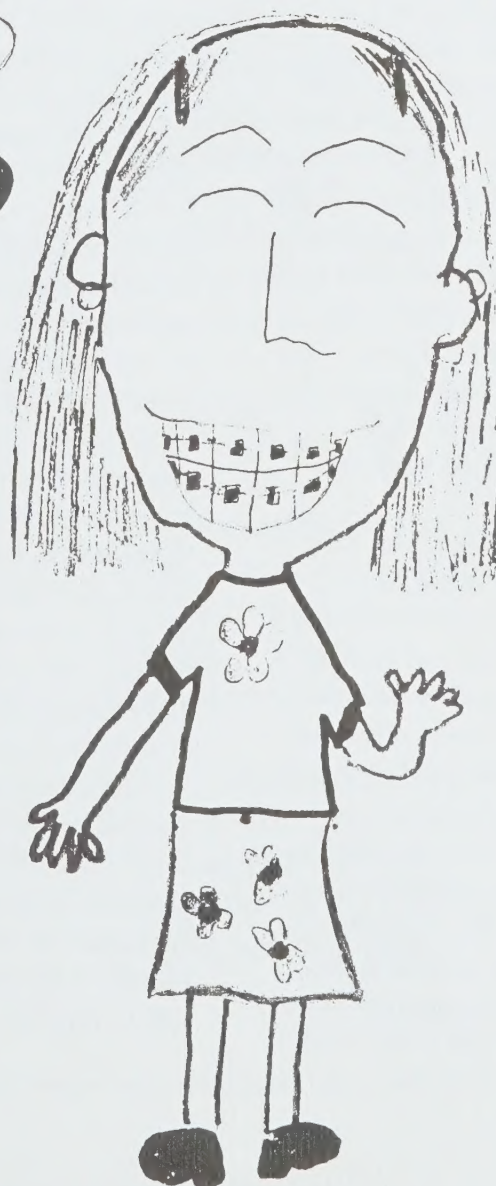
published by
Sharing to Learn

AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 13, NO. 2/JUNE 1996

JORDAN & CANDYCE

Brother and sister
Best friends



Families and Parenting

TRACY SHEPHERD &
SHIRLEY McNAUGHTON

From Tracy

I've been an Associate Editor for **Communicating Together** now for a full year and it is my turn to coordinate an issue. Recently, at the annual meeting I had the opportunity to meet and spent the weekend with the other editors. The flurry of discussion was exciting and very thought provoking. I found the mix of editors offered a well rounded discussion of the issues that were entertained. As the informal meeting ended late in the evening it sent the participants away to ponder what had transpired in the first day of meetings and brought us back together in the morning with some interesting ideas for themes. These dynamic individuals who have been bringing you wonderful issues of the magazine, should be commended for their enthusiasm and dedication to delivering an excellent and entertaining issue four times a year. I am sure as you read through the articles in this issue on *Families and Parenting* you will find no exception.

The idea for an issue with input from families came to me as an offshoot of the rationale for Family Centered Care. Treatment centers have adjusted to keep in mind the needs of the entire family and have gotten away from the medical model approach. I felt that our readers would like to hear from the families of individuals with communication impairments since they know them the best. Let's hear their thoughts, ideas and feelings. In my five years as a speech pathologist in the field

of Augmentative Communication I can honestly say that I have learned most from the families and clients themselves. Interpersonal skills and dealing with family issues are not included in the courses you have to complete to attain a Master's degree, but knowledge in these areas is vital to having good relationships. Collaborative relationships are the cornerstone of intervention techniques that are accepted and successful.

We certainly did not have a shortage of articles for this topic. It was exciting to read the articles as they rolled in, and I enjoyed being on the cutting edge of putting the issue together. In fact the topic presented such interest that we ended up having more articles than we could fit into just one issue. You can look forward to a carry over of articles on *Families and Parenting* in our September issue.

As the feature article this issue Shirley McNaughton and Peter Lindsay suggested we select my article on *Sibshops*. I am pleased to share the learning that we are deriving from our work with siblings. It seems to be a fitting introduction to an issue relating to family matters. This article was a pleasure to research and write. I enjoyed getting to know some of my clients' family members on a more personal basis. I talked with the coordinator of the *Sibshop* program in our center and chatted with a number of kids who had attended the workshops. Their thoughts are "pretty neat".

We are happy, as well, to follow our feature article with a tribute to Cam Calfus. We want to share the touching sentiments from Cam's Participation House "family" and friends in the issue which we dedicate to families.

In Nola's column she gets to the heart of some of her personal experiences and family matters. The manner in which she has had to adapt and grow as changes have arisen in her life is remarkable. She has met every challenge presented to her, always with a little help from family and friends. Nola's aunt, Needra Bennett, also shares her perspective of family, discussing differences she has observed having two individuals in their family with very different disabilities.

In *Perspectives*, Donna Joslin writes about her unique family and how roles and responsibilities have changed since she has been diagnosed with a degenerative neurological condition. She explains how, as her abilities have changed, her children have had to adapt and parenting has seen many obstacles. This exceptional article is a very touching sentiment from a woman who loves nothing in this world more than her kids and would give them the world if she had the key. Also, Linda Stanczak presents a picture of the challenges facing a family blessed with quadruplets. She discusses her son Colin who has hurdled many obstacles placed before him in his five short years. I commend a family who can be so busy with everyday routine yet strive to be so involved with activities at a rehabilitation center (as well as agreeing to write an article for our magazine).

In this issue, we have also reprinted an article by Michael Williams in which he discusses in a light hearted manner some of the little quirks in his family and how parenting for them, although slightly different, operates on the same principles as other families. Brian Pamplin's and Alda Stepran's

articles provide us with heart warming messages. Brian's words for **Communicating Together** come after some serious health complications. We are pleased he continues to share with us. *Paul's Place* raises the issue of society as parents. Paul Marshall opens the topic of global parenthood and how we all should act as parents setting appropriate and admirable examples for all generations. Paul also brings a personal touch to the topic.

Remember to look for more articles on Families and Parenting in the next issue. In Alda's next article she discusses families and parenting in Latvia. Shirley will share some thoughts about two great families celebrating thirtieth birthdays. A submission from Victor Valentic will offer the insights of an AAC user regarding his special family.

In future issues, look forward to:
Generation X (September 1996);
Differences across the Decades (December 1996);
Education and Employment (March 1997);
Spirituality (June 1997);
Our Anniversary Issue (September 1997);
Sexuality (December 1997).

From Shirley

At our annual Associate Editors Meeting, lots of formal and informal discussions occurred throughout the two days. One of them had a strong impact! It occurred at the end of our first day, with only six of us remaining at the dinner table. Suzanne Clancy asked, "What are the AAC users doing who are now in their early twenties? I am not seeing them enter college programs after leaving high school." Her question stimulated much thought as others in the group considered how the life situations of those now

in their twenties differed from those in their thirties, who we were seeing in college Continuing Education programs. The next morning, our after-dinner conversation resulted in my proposing, and undertaking to coordinate the December, 1996 issue, with a theme entitled *Decade Differences*. Some reading I have been doing lately, which I will share with you in December, is leading me to change the name of the theme to *Cohort Differences*. What are the

differences in the life situations of those AAC users who are now in their 40's, 30's, 20's, teens, pre-teens? I invite you to look ahead with me by looking back. Please send your thoughts, and personal experiences and observations to Shirley McNaughton c/o Sharing to Learn. They are needed by November 1, 1996 for them to be considered for the December issue of **Communicating Together**. §

The following poem was written by Christine Jimenez and submitted by her tutor Maria Wright to the National Library of Poetry Competition, September, 1995. It has been previously published in the Newsletter of the YMCA of Hamilton, Burlington, Ontario, Canada, June, 1995. What better thoughts to begin an issue on Family and Parenting!

A Child is Love

A child likes to play
 He is forever learning
 He is a curious child
 He asks many questions
 We try to explain the answers
 But a child will argue
 That he is right
 And we are wrong.

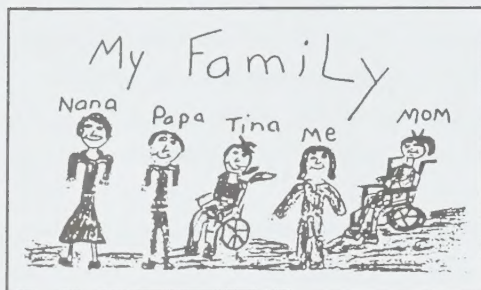
We try to protect him
 We try to forget
 That one day
 He will stand on his own
 We must be able to tell him
 How much we truly care
 Not only in words
 But in others ways as well.

As we watch this child grow
 We wish him only the best
 The most precious thing
 We can offer is our unselfish love
 Because a child is love.

Christine Jimenez, 1994.

YOUR BROTHER HAS CP?! SO DOES MINE!

TRACY SHEPHERD



by Jennifer Dumaine

As coordinator of this issue focussing on Families and Parenting, Tracy Shepherd introduces us to several families she has come to know in her role as speech-language-pathologist at the Children's Rehabilitation Centre, Windsor, Ontario, Canada. In this article describing the Sibshop program at her centre, we have the good fortune of meeting several young family members who have siblings with special needs.

"Boy, now I know how my brother feels!"

"Wow, I never knew she had to work so hard."

These are comments heard at sibling workshops taking place throughout the province. We have so much to learn from siblings in order to best address their needs and those of the entire family. Studies have discussed the effects on siblings of children with disabilities and how they have different and unusual opportunities presented to them over their youthful years. Benefits such as increased understanding, increased tolerance, compassion and appreciation of good health and intelligence have been reported

(Grossman, 1972). Although there are these recognized advantages there are also difficulties which need an avenue to be discussed. *Sibshops* are meetings or workshops planned with the needs of young siblings in mind. Some of the goals of the workshops include:

- providing siblings with an opportunity to meet other siblings in a relaxed, recreational setting.
- providing an opportunity to discuss common joys and concerns
- providing an opportunity to learn how others handle situations commonly experienced by siblings
- providing siblings with an opportunity to learn more about the implications of their brothers' or sisters' handicaps
- providing parents with an opportunity to learn about common sibling concerns (Meyer, Vadasy & Fewell 1985).

Judy Landry, a social worker at the Children's Rehabilitation Centre, along with the siblings I spoke with, made me aware of the types of activities that take place during these annual workshops. The therapy departments volunteer to do demonstrations. For example, the communication therapy department taught kids some signs and had them conversing with the signs they had learned. While this activity progressed, there was a concern that they "really don't know what their siblings are thinking" and the sibs were afraid that the signing might be

limiting. What an insightful comment! The kids were also asked to fill their mouth with marshmallows and try to talk to their peers. Jennifer Dumaine explained to me later, that if you knew how to do it right, you could eat the marshmallows while talking and as you had fewer in your mouth talking became easier.

Occupational therapy had kids putting on oversized gloves and trying to build block towers or put pegs in holes. They also tied one or both hands behind their back to complete some tasks in order to simulate the difficulties their sibling might encounter. Physical therapy set up a wheel chair obstacle course and had kids trying to complete functional activities while in a wheelchair. Judy's concern was that the siblings found this to be a FUN activity. Judy has found in discussions with disabled kids, that they get angry when comments are made such as, "It's fun to be in a wheelchair". The kids I talked to realized that it may be fun for five minutes, but try it for a lifetime! The Augmentative Communication Clinic set up simulation activities such as using switches and scanning to operate computers. It was noted during these session that using a computer may not be as much fun as the siblings thought. Using such a slow method of access sure took the fun out of drawing pictures with Kid Pix. One child was heard saying "Now I know why my brother is so excited when he can do something!" The jealousy over their siblings being on the computer "all the time" seemed to subside after they had gained this

understanding. The kids also tried to perform tasks with glasses on that simulated various visual deficits. Comments were noted, such as "Is this really how my sister sees?" Judy described the workshops as "a resounding success". If she were to change something she would limit the age groups to a smaller range, to allow kids to feel more comfortable talking and opening up. She saw shy, tense kids come into the workshops in the morning and by the end of the day there was a group of new friends chattering and interacting. The sibs group recently had a reunion in which they began to plan more frequent sib groups. They would like to have them every two weeks. At the end of the program each child is presented with an award and some literature to take home for mom and dad to read. The Easter Seal Society has been instrumental in the Windsor area in getting donations and helping out during the *Sibshops*. Easter Seals provides parents with some helpful hints in dealing with siblings such as:

- use family conferences as an open forum to ask questions, talk about feelings and legitimize reasonable anger
- find manageable ways to spend individual time with each sibling
- don't tackle problems as a whole. Break them into manageable parts.

Handouts provided by Easter Seals encourage the involvement of mature siblings in the decision-making process as much as possible.

"Kid's Corner"

Siblings Speak Out

Recently, I have been talking to siblings who have a brother or sister with a disability and have attended a

Sibshop. They all spoke highly of the activities and said they would love to do it again. These siblings were great about sharing their feelings; however, since our relationships did not have time to develop, I didn't get to the heart of many of the issues. I only scratched the surface. The important thing about the *Sibshop* is that it allows these kids the opportunity to really get to know each other and get down to the heart of matters that might be upsetting and important. I invite any siblings out there to share your thoughts with us by sending us your experiences with your disabled brother or sister.

From Jennifer Dumaine

Jennifer is in grade 5 and is ten years old. She finds herself with two very important individuals in her life, both of whom have been left with a disability after a motor vehicle accident. Jennifer herself was not involved in the accident. However, her mom and her younger sister Tina sustained head injuries. The family now lives with Jennifer's Nana and Papa.

Jennifer and I talked about teasing. She explained that she teases Tina about getting to go swimming. When Tina is in the pool everybody else has to get out, although Jennifer can go in any time. Even though she herself was guilty of teasing Tina, Jennifer didn't think it was very nice to tease.

Jennifer is pleased that Tina has a computer because she and the rest of the family get to use it. One thing that Jennifer doesn't like is going into Tina's room. She says once you get in it's hard to get out. Tina will "keep you in there all day; she wants to play with you." Jen explained. Jennifer likes to bug Tina sometimes *but* Tina will tell Nana and Jennifer ends up getting in trouble.

Another thing that Jennifer likes is hanging out with Tina and her home worker, Lesley. She gets to go to the mall, to the movies or to the store with them and that is "pretty cool". Jen mentioned that Tina gets to go neat places like Disney World and wished she could go too. But Nana is planning a trip for the family in the future. Jennifer can't wait!

From Candyce Dube

I talked to Candyce whose brother Jordan has cerebral palsy. Candyce was thirteen years old in May and is in grade 7. Candyce is happy that she doesn't have to fight with Jordan, like other siblings often do. Since Jordan is non-verbal, he doesn't mouth back to her (much). She is pleased that she gets to hang out with Jordan more than the average kid. She thought that if he wasn't in the wheelchair he might be out with his friends more and that she wouldn't get to see him. Like Jennifer, she felt it was cool to get to hang out with Jordan and his in-home worker on the weekends. They do "lots of stuff" together. Sometimes her friends get to come along too. Candyce says her parents pay as much attention to her as they do to Jordan so she never worries about that. She did feel that Jordan gets his own way a lot and that her parents worry about and are more cautious with him. On the topic of teasing Candyce says she can't tease Jordan because he will yell or pout and then she gets in trouble. She feels they communicate pretty well together and she usually knows what Jordan wants. Something that gets on her nerves is when she takes Jordan for a walk, people stare at them, or look at them funny. This makes her mad, "How would they like to be pushing the wheelchair?" Overall she loves Jordan for being who he is, "not a pain in the butt".

From Paul Beneteau

Lastly, I talked to a brother-sister duo. Their brother Marc is five years old and has special needs. Paul is nine years old and in grade three. When asked how he would describe his younger brother he replied "a normal kid". He wondered how he was going to do playing baseball, since this will be his first summer. The best thing Paul thought about Marc is that he is "fun to play with", but he has to be careful because sometimes Marc gives him a fat lip. Paul goes easy on Marc when they rough-house so that he doesn't get in trouble. One thing Paul doesn't like is sleeping in the same room as Marc. He claims that Marc breathes too heavily when he sleeps and it is hard for Paul catch some "zzzz's." Sometimes it gets on Paul's nerves when his friends come over and end up playing with Marc or when Marc steals his knife at the supper table. One time Marc got mad at the supper table and slammed his fist onto the table. Paul explained, food went everywhere. Paul

thought that Marc tends to get more sympathy from Mom when he cries whereas Paul and Julie go to Dad. Mom worries a lot about Marc's seizures. Paul used to wish that Marc could play hockey but now Marc can score on him. So now he just hopes he does well in baseball this summer.

From Julie Beneteau

Julie is Marc's eleven-year-old sister who is in grade 6. She describes Mark as talented since he is so flexible and she likes the fact that he hasn't grown out of his "cuteness". She likes to play baseball with him and read books to him. Sometimes it gets on her nerves when he watches Barney all day long or hogs the TV and VCR. Sometimes Marc gets more attention, because he gets to do activities like swimming or horseback riding, but "Mom and Dad try to give us the same amount". If she could change one thing she would not want Marc to have seizures. Julie finds it pretty easy to communicate with Mark. He uses his signs and words and his

Macaw voice output device and if she still doesn't understand him, then she will ask Mom because she usually knows.

I enjoyed preparing to write this article and getting to know the brothers and sisters of the some of the kids I work with a little better. Over all they seemed to have alot in common with one another. Its no wonder the *Sibshops* work so well. The unique experience of having a disabled sibling has given them plenty of insight into people and into their own families. This will be an invaluable strength as these kids get older.

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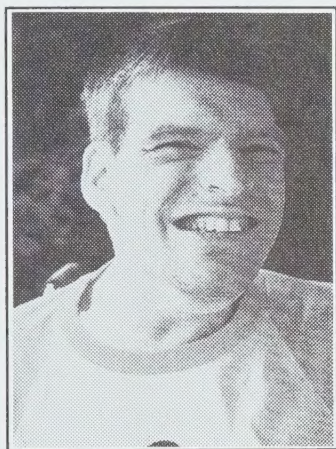
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A TRIBUTE TO CAM CALFAS

CAM'S PH FAMILY
& SHIRLEY McNAUGHTON



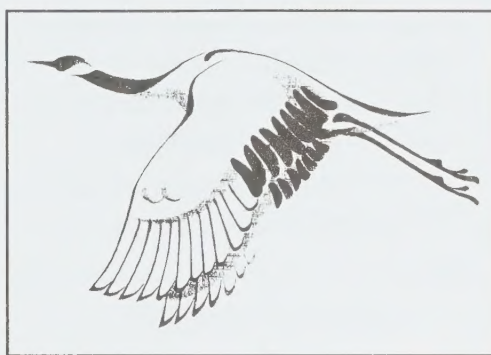
Cam Calfas

*As we devote this issue of **Communicating Together** to family, it seems most fitting to include a tribute to Cam Calfas who passed away on January 31, 1996. His extended Participation House family was a large and caring one.*

From Shirley

I first met Cam when he approached me and made me aware that he would like to be involved in the research I was doing with some of his fellow residents at Participation House (PH), Brantford. Cam used speech and Blissymbols to communicate with his family and his many friends. He had many interests, including swimming, art, music, church, games training. What his many friends remember most is his hearty laugh, his love of teasing others, his caring and his bravery during his final months with cancer. He often seemed to be more concerned with how his illness was affecting his family and friends than about himself. Following are some of the sentiments expressed by Cam's PH family, following his death. He was greatly loved by many!

*You're free my Son
Free of life's chain
Free with the Spirit of the Lord
You're free my Son.
Soar like the eagle
Run like the deer
Sing like the nightingale
You're free my Son
You're free.*



*Cerebral palsy
didn't keep you down.
You taught us so much.
You'll be in our hearts forever.*

Memories of Cam's Friends

Lynn

I want you to know how privileged I feel, and how touched I am that your mom and dad asked me to say a few words today. I chose to read you a letter because I know you are with us in your own special way.

You came into my life, and the life of Participation House, 17 years ago. The first time I saw your impish little grin I knew you had character. Just how much I would find out through the years.

We have laughed together, cried together but the most important thing we found out together is that all people have challenges in life and if

you find someone to work things through with, most obstacles can be met. You and I found each other.

Your dad said, "Our home will be quieter now". Yes, Cam, things will be different. We can't see you, hear you or hug you, but memories of you will always be vivid from the years you made our home your home.

As I walk around PH, I can see you in the laundry room chatting with Jan and Dora, or slurping back a Tim Horton's coffee with Marilyn. Remember how you would teasingly chase staff down the hall to get a whiff of their coffee? In the ILC, I see you painting. Cam, if only you knew how much pleasure your painting has brought your family and friends. You always ended up with birds in your work. You told me this meant freedom to you. Well Cam, you're free now. I remember the day you mastered painting musical notes. All you said was, "Wow", but the sparkle in your eye told me the rest.

When I sit in my office I think of all the serious talks we had. Remember Cam, you would call this "the old nag time", or sometimes you would drop in, sing a tune with Anne and get pizza money. You kept the pizza places in business.

Your room is where I am sure resident care staff have many fond memories of you. I know they were happy ones because sometimes I would hear you laughing when I was in my office. Oh Cam, that laugh! When you found something funny, your laugh would come straight from your stomach. Like your singing, your laughter would ring through the halls of PH.

Your friends want to thank you
for all the special memories you
have given them through the years.
Your laughter brightened our day,
and your caring showed us we were
loved by you. Cam, in the last few
days many stories have been shared
about you by a lot of people, but the
one thing they all have in common is
the love they have for you.

There is always a place in heaven
for very special angels, and I know
that is where you are, Cam. Actually
you will always be in two places, in
our hearts and in heaven.

Daryl

Cam was not just a resident of PH
He was a part of the family of friends.
Although each day he will be sadly
missed,
His smile will never ever end.

Each day we will carry with us
The memories we made together
For it is those memories of him
That will make the days better.

So we say farewell to one of our
friends
Never to say goodbye for good.
Our memories of him will never end
For he has a special place within our
hearts
And impacted our lives
Like only Jammer could.

*The following tributes were
expressed originally in
Blissymbols:*

Roberto

Cam could always make people
understand.
Cam helped me inside, to learn to
read and in the Bliss class.
He was a friend.
He had family love.

Paul

Sunday he liked church.

David

Cam was a loving man. I remem-
ber communicating with him.

Robert

When I moved to PH, I shared a
room with a stranger. His name was
Cam. Cam and I became friends. We
went to the track meet together. We
watched television sports. Cam
loved to swim in the pool or lake. I
miss him. He was my best friend!

Val

Cam was my friend. In the
morning he awoke laughing. He
went to work. He did art. Cam
painted pictures, cards and shirts.
Cam loved to tease me. Sometimes I
got angry but now I miss his teasing
and I miss Cam!

*Thanks to Anne O'Malley for
sharing the tribute to Cam made by
his PH family.*

§

*This poem was given to Martin Humm by his brother, Nevel. It hangs in
Martyn's room at Participation House, Brantford, Ontario. We thank Martyn for
agreeing to share it with our readers.*

To My Brother

Together we shared a child's world.
We talked, we disagreed,
We shared personal hurts and joys,
And the older we grew,
The stronger the bond between us
became.
I was always so proud to have you as
My brother.

Now Life has taken us down separate
Paths, but your well-being and happiness
Will always be foremost in my thoughts.
Neither the span of miles nor years
Between us can ever change the feelings
I have for you... I love you.

NOLA MILLIN



Nola Millin

This time Nola leaves her role of editor of Yuks & Wows to share her thoughts and feelings on her family. She discusses her struggles and milestones as her family changed and grew. Nola's aunt, Needra Bennett, also contributes her perspective of family.

Since this issue is dealing with family, I have decided to write about mine. I feel the word *family* is difficult for me to really define because I have many people who make up my family — some related and others not. I have grown up with strong family values. My family not only gives me the love and encouragement I need but they also give me physical and emotional support. This support is important to anyone at any time but for a family of an AAC user it can be extremely challenging and at times very consuming to give.

I was an only child, born with CP and a speech impairment. My parents

were in their thirties when they had me. I feel their maturity was a hidden blessing for me. I remember my mom would always talk to me and she refused to use baby talk. Because I had a lot of stimulus around me, I grew up wanting to communicate. My parents were great at understanding my grunts and gestures, so my needs were met when I was younger.

**“My mom . . . let me make
my own decisions
to teach me that
there are consequences
to the decisions I make.”**

I thank God for my mom because she thought of ways for me to communicate. Mom believed in independence right from the start. She felt that I had choices to make and I should be allowed to make them despite my limited speech. I remember many times my mom would ask me what I wanted to eat. She would give me the options, then would repeat each one and wait for my nod “yes” or “no”. This method taught me how to make decisions while eliminating the frustration of not being able to verbalize my decisions. I feel I learned how to be independent by having choices to make at a young age. Obviously, my mom didn't let me make any decisions that would harm my life but she let me make some bad decisions to teach me that there are consequences to the decisions I make.

As I grew older, communicating became very important to me. I had

things I wanted to say but no means of saying them. I remember when my father died prior to my seventh birthday, I became worried about something happening to my mom and I wouldn't be able to get help. My mom realized my fears were legitimate so she installed a burglar alarm in my bedroom. She gave keys to various neighbours and the alarm company was instructed to call these people if the alarm ever went off. This burglar alarm gave me peace of mind because I had a way of communicating with the outside world in an emergency.

The Christmas of 1970 changed my life. That Christmas I received my first electric typewriter. With the help of picture dictionaries and second grade spelling, I could compose messages to my mom and other people. Since a typewriter isn't portable, my mom developed an alphabet board that I could carry around. Although my spelling was limited, I was still able to communicate.

My communication abilities opened up at age 8 when I was introduced to Blissymbols. I was literate so I was able to read the words while I learned the symbols. I quickly advanced to the 500 symbol board — it was the biggest board I had ever had! My mom never mastered Bliss but that didn't stop me; she would just read the words as I pointed to them.

As my abilities to communicate opened up so did my social life. I lived in a small rural neighbourhood and a lot of the children accepted me into their circle of friends. My mom made our house the place the kids

could come to play. I had some neat toys, too! The kids didn't just come to play with my toys though. They came to play with me. I was always included in whatever game we were playing even if I had to be a referee. As I got older my mom allowed me to go places with my friends. I slept over at their houses and I went to the movies or other places with them. I'm sure it was hard on my mom to let me go but she realized that all of my friends knew how to take care of me. I'm grateful to my mom for allowing me to be independent. Raising me to be independent was the greatest gift my mom ever gave to me.

Unfortunately, my mom was killed in a car accident when I was 14. My relatives all live in the United States but I chose to remain in Canada with my step-father. Since I was independent, I was able to communicate my desires and fortunately my relatives respected my desires. I lived with my step-father until he died when I was 17. At the age of 17, I moved into an apartment complex that has round-the-clock attendant care, where I am still living today.

As the years passed, many communication devices became available to me. I tried various electronic devices, but none seemed to work as well as my word board. My need to communicate with my relatives, especially my uncle, grew because he was my legal guardian. My uncle was able to get a TDD donated to me. This was great for communicating to him but it was very limiting. I could communicate over the phone with people who were close to me, but this was also limited. Unfortunately, my relatives weren't around me enough to decipher my speech over the phone.

When they come to visit, they can understand some of my speech. They rely on my word board a lot!

As you can understand, my "family" has changed with the events that have happened in my life. Although I love my relatives dearly, they don't live close enough to be able to help me when I need it. Fortunately, I'm blessed with many good friends. One of these friends is my "other mother". She started taking care of me when I was 6 months old. I now call her Mom. She is there when I need someone. Another friend gets my groceries each week. He also fixes things in my apartment or on my computer. I have other friends who help me in various ways. These friends have become my family. With their help, I can be as independent as my disability allows.

For me, it is essential to have the love and support of my "family". As I try to maintain my independence, I need people who will give me the physical and emotional support I require. Equipment often breaks down, or I need to go somewhere quickly. I can call a friend. Yes, I'm independent in that I make my own decisions but I'm dependent on a loving "family" in supporting these decisions.

Within the last three years, I have become even more independent thanks to technology. I have gotten a phone communicator that allows me to talk over the phone. I also have gotten a lap-top computer with a voice synthesizer. I'm now able to communicate with anyone who is willing to listen! These devices allow me to stay in touch with my family and friends.

As an AAC user I'm very thankful for the family I have had and the one I have now. They have been my

support through thick and thin. I realize it hasn't always been easy communicating with me and finding out my needs but I'm glad that people didn't give up on me. I'm thankful that my mom raised me to be independent and that my family has allowed me to remain that way. It is with this independence that I have the opportunity to achieve many things and to learn how to communicate freely with the world around me. I've seen many disabled people who have been hampered by their families or who don't have the support of a loving family, so I feel really blessed for my "family".

Now, my aunt, Needra Bennett, will share some of her thoughts:

Many of you are well versed in dealing with the person with special needs in your family or circle of friends. Possibly involvement with various organizations and activities throughout the years has brought you into contact with others who have similar needs. Very few families have two members with two entirely different disabilities as ours does.

You are all familiar with our niece, Nola Millin, through her writing and editing capabilities with this magazine. Our family is very proud of her — of her perseverance in getting her education, of her involvement in various organizations, of her work on committees, not to mention her work on **Communicating Together**. Family involvement has been much less than we would all like, since all of Nola's family is scattered throughout the United States, beginning in Michigan and including Florida and North Carolina.

Nola was 14 when her mother died, but she was adamant that she did not want to leave Canada to live with a relative in the States. She was 17 when her step-father died, leaving her totally alone. Again, although she was not yet an adult, she took charge of her life and made her own decisions. The apartment building that has attendant care, where she is living, made an exception allowing her to move into the "adult" building months before she would actually be eligible.

We also have a grandson who is autistic. Kevin is 21 now and he lives relatively independently. His family has a "guest house" on their property where Kevin lives alone. He keeps home for himself, fixing his own breakfast and lunch, and then joins the family for dinner. Of course, he has access to the family home whenever anyone is there, and whenever he chooses to join them. When his autism takes over and he begins to be disruptive, he can go to his own home and not disturb the others. He works at an adult workshop each day and he is able to set his alarm, pack his lunch and be ready for his ride. He also enjoys going on field trips.

There is a wide gulf between cerebral palsy and autism. Nola has a very high IQ and mental capabilities, enhanced by her Bachelor's and Honours Degrees, but she is held back by the physical restrictions of cerebral palsy. Kevin has a perfect body and excellent health, but it is very hard to know what is going on in his mind. Science has been able to determine very little about autism.

Nowhere is this difference more apparent than in communication. We have watched Nola progress from her "word board" (which we still refer to more than we like to

admit), through several electronic devices. We are totally amazed at the technology available to her now — her phone communicator and lap top computer with voice synthesizer make it possible for her to communicate, even when talking to someone for the first time. On occasion she has been able to save a speech or presentation she has made to play back for us. Since the family is not close by, this allows us some insight into her many public responsibilities.

**"The gulf between
cerebral palsy and autism
is very apparent
in communication."**

Communicating with Kevin is totally different. Although he talks non stop and his speech is very understandable, most of what he says could not be considered communication. He can type 50 words per minute, however, typing is used just for his school, employment, or personal entertainment. One typing project he did was to help the library enter their 3 x 5 card system into the computer. This was a task well suited for him, as accuracy was required and Kevin is a perfectionist. It is not in his nature to accept an error. Typing has been a real advantage to him, but he has never tried to communicate with someone with his typewriter.

We have been puzzled about this, since he sits at the computer and creates very imaginative stories, such as having lunch with a celebrity. His stories usually make no sense at all, but it does give us insight as to what is going on in his mind. Because our efforts to communicate on the computer or typewriter came to no

avail, we have never had much faith in "Facilitation". Kevin has no problem making his needs known, but will usually limit his responses to questions, to yes or no. He is the acknowledged expert in the family when it comes to Nintendo type games. It is almost an anomaly to watch his brother or sister work their way through a game to a difficult spot then call Kevin to take them past it.

We do not know what the future holds for these two with their special needs. While we rejoice in each of Nola's accomplishments, she has many needs which are often frustratingly out of her reach. Although she can never overcome the crippling effects of cerebral palsy, we feel that Kevin will never be able to attain the level of independence that she has reached.

§

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Words From An Old Crock'n Roll Mom

DONNA JOSLIN

Donna Joslin is a dynamic parent whose family is unique and quite lovable. She explains how her role as a parent has changed since her diagnosis with multiple sclerosis. We are very pleased to have her contribution to this issue.

When asked to elaborate on the topic, parenting with a disability, I couldn't help but think that, were it not for their literacy difficulties, my children might legitimately have as much to divulge on the subject as I. This subtle alteration in our family's respective roles had somehow escaped my notice until an observer's recent perception made me suddenly aware of how much our relationships have evolved into a network of mutual support, even from the weakest link in the connection. While my role as parent is still the dominant one, my dependence on my children's patience, tolerance, cooperation and willingness to fill in the gaps is undoubtedly critical to our strength and unity. Before you form a mental image of a wheelchair-bound mom attended happily by her errand-running children, let me describe my unique family.

Nicole, the youngest, and the one who comes closest to fitting the expected image, is 17, a survivor of a neuroblastoma that left her learning disabled, speech and language impaired, and chronically subject to infection through a damaged im-

mune system. In those few words, I have covered all her weaknesses, for in every other respect she is the most perfect person I have ever had the good fortune to meet. She came to bless our lives at the delightful age of 33 months, and from that time on, I have never ceased to marvel at the beauty of her nature.

Can you imagine a child who has never known anger, resentment, jealousy, covetousness, or even irritability? A girl who lavishes affection on her parents and siblings, perceives and tries to fill their slightest need, finds exuberant happiness in just daily living? I wish

**"I never knew
what Angel's world
was like until
I began to live it myself."**

I could say that my parenting had a lot to do with it. I hope I nurtured it, but I know, darn it, that I didn't have a lot to do with it. Never wanting her to feel burdened by her family, I've probably imposed less responsibility on Nicole than most girls her age, so her loving helpfulness is almost entirely spontaneous and self-motivated.

One of my greatest treasures is the memory of her 14-year-old school composition, prompted by the question, "If you could have or do anything in the world, what would you choose as your ultimate goal for happiness?" Nicole wrote, "There isn't anything in the world that could make me as happy as just being at home with my mom."

Next is Angel, age 23, a severely cerebral palsied, hearing-impaired, non-verbal quadriplegic. She is an electronic virtuoso, liberated by a hi-tech power wheelchair and Dynavox communication device, that she operates proficiently by an array of head switches. Complications from surgery to correct a severe spinal curvature have made her totally dependent on tube feeding for survival. Angel is also an extraordinarily happy girl, very accomplished socially, with a delightful sense of humour. She has been the object of Nicole's tender and solicitous ministrations from the first day of their meeting, sometimes, in the younger's early and awkward childhood, to the point of desperate appeals for rescue. On the whole, though, Angel has rarely been forced to totally deal with the enormous limitations of her body, thanks to the companionship, intervention, and devotion of her sister.

Angel's special contribution to the family's survival has been not only the contagion of the stars in her eyes, but her ability to keep us all on the straight and narrow, reminding us with her Dynavox or eye-pointing, of a multitude of forgotten or overlooked details. Of course, her quickness to perceive and laugh at the incongruous has certainly helped to keep our difficulties in perspective. When I now confront with anger and frustration many of the obstacles and encumbrances Angel has faced with equanimity all her life, I am repeatedly moved to greater and greater levels of respect. As sensitive as I thought I was to every facet of her world, I never even came close to knowing what it

was really like until I began to live it myself. The mother now has most to learn from her daughter.

Next oldest is Amy, 24, deaf-blind, hydrocephalic, non-verbal, obsessive-compulsive, and dubbed "Radar" through her extraordinary sensitivity to vibration. She is the only deaf-blind person known to have learned language comprehension through a speaking communication device. Quick to perceive the rationale and the multitude of ramifications behind the stringing together of symbols (ideas), followed by the memorization of the vibrations felt from the spoken output, she developed a wealth of appropriate expressive vocabulary (electronic), and more gradually, a working recognition of language by the human voice. Amy doesn't allow me to nurse my wounds for too long. As subtle as a Sherman tank, when she thinks I've had enough recouped time, she makes me get up and get on with it through implacable persistence, and if necessary, sheer physical force. After all, I did the same thing to her all those years when I moved her arms and legs in quadruped position for 5 to 6 hours a day, coaxing her damaged cervical spine to regenerate. Add more years of pushing and experimentation towards language development, and Amy's entire childhood was sacrificed to the quest for liberation. Closeted and deprived of human contact for the first six years of her life, Amy was turned completely inward when I adopted her, unapproachable and unmanageable.

We struck an unspoken deal then, through a developing bond of trust, that she would do the things I wanted her to do if I reciprocated by sharing and respecting her strange, ritualistic activities without judgment. I expected a lot. Looking back, I had no idea of the enormity of the expecta-

tions I placed upon her in my blind optimism. But Amy delivered with the impossible. With every setback, she got up and tried again and again. Now this tough little cookie makes me do the same, with no excuses. I guess I have it coming.

The oldest is David, 34, my natural son and the reason for adoption of my three girls. Dave has cerebral palsy and a speech impairment. But he is everybody's favourite guy. Always our goodwill ambassador, finely tuned to the limits of his welcome, he makes lasting friends wherever he goes. Sometimes chagrined by the vastly superior ease with which he cracks the social ice, I marvel at the widespread extent of his popularity. Would that I could cultivate his secret! Plagued with life-threatening breathing difficulties during his first five years of life, Dave's joy of life nonetheless continuously bubbled over.

In a society at the time of his boyhood devoid of resources, David followed a rigorous home regimen developed by an experimental program in Philadelphia that required 12 hours of hard therapeutic exercises daily. For 8 years, David bounced and bubbled his way through a regime that made army boot camp look like kindergarten, never complaining and always finding something to be happy about no matter how bleak the circumstances. When school finally opened to him at age 16, it was only natural that I should want to repeat the bountiful rewards with other injured children that David had given me.

When Dave was 26, he "became a man" emotionally, and separated himself figuratively and physically from his family. Though under the same roof, he resides in his own self-contained apartment. Despite his developmental limitations, I have

every reason to take great pride in his independence knowing he'll always be OK, no matter what.

A couple of years ago, Dave's hard earned mobility began to degenerate. Now he has to use a cane and a power scooter outdoors. In addition to his cerebral palsy, it appears my genetic legacy has endowed him with my affliction - multiple sclerosis. Even yet, I have reason to shake my head and marvel at his irrepressible optimism - he takes it all so much in stride. Damn kids! How can I be properly disabled when they set me such an annoying example!

Since I was 33 (I'm now 64), I had been plagued with frequent vascular headaches and bouts of "seasickness" and double vision. In my 30's, I had 3 attacks of severe neurological trauma that temporarily immobilized me. Never diagnosed, I was unwilling to let these thorns in my side run my life, so I packed it so full that I had little time to give them my attention. For 25 years, I worked a 20 hour day and set myself up for one challenge after another. I had a fantastic life - the rewards were beyond belief. Five years ago, following knee replacement surgery, I suffered extensive nerve damage to my left side. I felt so traumatized with pain and a prolonged sense of "shock" for several months, that I really thought I was going to die. I couldn't drag my body across the room without blacking out. Angel's anxious eyes never left my face, and Nicole tirelessly ministered to my needs. At first, Amy reluctantly allowed me limited quarter, then furiously decided enough was enough. When physical strength failed to drag me to my feet, she pounded through the house stamping her feet, and let me know in every possible way how angry and be-

trayed she felt. Amy doesn't give up — ever! The little rat just wouldn't let me die. Conversely, I also came to depend heavily on Nicole's total unselfishness and devotion to me. I clung to it as to a lifeline, and it pulled me back. I fought hard for recovery and thought I'd made it, when I felt that creeping paralysis start down my good side. Thereafter, I was hit again and again and again.

The diagnosis was multiple sclerosis.

Following the shock and adjustment to the probability that I was becoming, of all things, a quadriplegic, I must confess I rather expected to be looked after. I'm not sure whom I thought was going to do the honours, but it wasn't long before it became very clear that my responsibilities and workload were to continue with relatively little change. I was chagrined. It wasn't fair. But like all mothers whose right to be ill finds little recognition, I ruefully learned that having my brains fried was not going to get me out of work.

I'm not sure if it's this disease that's so odd, or if it's my reaction to it. When my brain and spinal cord are under attack (for 3 to 4 months at a time, twice a year), every fibre in my being cries to "hole up", escape to some dark corner where I can insulate myself from the agonizing stimuli of light and sound. But of course I can't. Denial keeps me on the verge of tears (and I was never a crier). The pain and exhaustion that hits me by 10 o'clock every morning is like the marathon runner's experience of "hitting the wall", when it feels like every cell in one's body is breaking down. Flooded by such intense weakness, but forced to drag myself always further, the need to escape this agony becomes so intense that I long desperately for death. I consider various means of suicide, but I think of my kids,

especially Nicole. She's only 17. She doesn't deserve this. So I keep going, and flirt with thoughts of suicide just so I can pretend there's a way out. When I go into remission, as I always seem to do, though I retain each time some further damage, I find myself believing that this time it will last. I can have my life back. I really forget how bad it was, and reproach myself for giving in to it. I guess I've always tended to forget the bad things and cherish the good. Maybe that's the strength and capacity for survival in human nature, this ability to selectively forget and remember.

This last winter, Nicole seemed to change. She removed herself from me emotionally, spent much more time in her room, or lost herself in TV. Even occasional requests for her help were met with sullen looks. I thought ruefully that she was finally in her emotional adolescence. I sorely missed her, though I said nothing. I have always raised my kids to leave me, at least as much as they can. That was the whole point. One day, in a weak moment, I asked her if I were doing something unintentionally to drive her away from me. She burst into tears, sobbing that she was only afraid that I was going to die. I reassured her that MS doesn't kill its hosts, just imprisons them for select periods of time. I told her that while I couldn't promise to live forever, I knew one thing for certain: that I would live immeasurably longer if I thought she needed me.

From that day on, her withdrawal ended, and the unity of our family was restored. In truth, the dire needs of my children are the only mastery I have over this capricious disease. I wish I could bottle the chemical that drives my tormentor into remission when my children are hospitalized. So far, it's a formidable weapon against it.

Amy has adjusted to my limitations. With every instance in which she's required to exercise a new degree of independence, she registers surprise and a little nervousness, but she cooperates to the best of her ability (though quick to draw the line just slightly short of imposed expectation). It's her way of striking a compromise and therefore exercising rightful control. On my better days when I bathe or dress her, the depth of happiness this simple indulgence gives her touches my heart. She allows me my weaknesses, but she's not about to let me off the hook entirely.

This last winter, I was laid waste neurologically. Barely able to move, and struggling just to breathe, I pleaded again for the impossible — a placement for Angel. For the last two years, I'd been denied any prospect that she might enter a group home, or find any other appropriate living arrangement. This time, a compassionate social worker exercised her influence to have Angel placed temporarily in the young adult unit of a local chronic care hospital. It was a beautiful place, and I had high hopes for possible permanency. Angel was thrilled, as her need for people is paramount. We both received, however, an unexpected but valuable education. I learned that there is no nursing facility that can by its very nature address the quality of life needs of a young patient totally dependent on high technology. I also learned that no matter how weak or ill a mother might be, she cannot bear the unhappiness of her child. Most of all I learned that, no matter how overwhelming the difficulties, there is no relief to be offered by the abdication of parenthood. Angel learned for the first time that her love of new people, of exercise of her social skills, is overwhelmingly secondary to the security and attention to her needs

that she enjoys through the love of her family. She moved back home. Given new insight for both of us, I perceived a new solution. I closed off the front half of our home and arranged the furnishings so that Angel has a separate apartment in that part of the house, with its own entrance. This enables her, hopefully, to not only develop a sense of independence and exploration of her own goals and responsibilities for self, but also provides her with a structure for outside care for basic needs.

Experimentally, Home Care and Special Services at Home may be sufficient to finance her own caregivers for high need times of each day. The proximity of her family may fill in the gaps by allowing her security, companionship and safety. Most importantly, this arrangement promises to allow me the privacy, peace and relief from total responsibility that my neurological fragility requires. Her caregivers can come and go, and hopefully will shift

their focus to Angel for direction, instead of constantly to me. It's time.

When I was very young, I read something to the effect that if one believed that happiness could only be acquired beyond the boundaries of one's own back yard, then the quest for happiness could never be attained. I can remember feeling somewhat indignant at that philosophy, since I perceived only a preponderance of despair and loneliness in my own back yard. Though life has since taught me many times that inherent in every problem, there's a solution, and that happiness only exists in the realm of one's own perception, it seemed that this time there was no possible way to reconcile the extent of my disabilities with the enormity of my responsibilities. How bizarre it is that little has changed in the last few weeks, and yet everything has changed, just by filling in an opening in a wall.

Parenting with a disability, at least for me, is hardly a state that I can recommend. It isn't rewarding or useful or strengthening, nor does it

offer any philosophical inspiration, no matter how you look at it. As a matter of fact, it's bloody hard and inconvenient, at times beyond belief. I don't mind the disability, it's parenting with it that's so tough. But when you look around you, some poor soul is battling cancer and chemotherapy, and somebody else is watching their child die of leukemia, and rotten things do happen to nice people.

But when it comes right down to it, I wouldn't trade one minute of my life for anybody else's and I thank God for every second of every day that my children have blessed my life. Even if all I can do next year is wink one eye, I'll still savour the rich feeling I get when my appearance makes Angel's day, the way I fill up inside when Amy's blind face is curved by a delicious, secret smile, the thankfulness I feel that I'm privileged to share space with an angel like Nicole, the contentment I derive from watching David happily make his own way in the world. I've got it made!

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AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
International Society for Augmentative and Alternative Communication*

Editor: **David R. Beukelman**, Professor of Communication Disorders,
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And a Baby Makes SIX!!

LINDA STANCZAK



Colin Stanczak

Linda Stanczak is a mother raising quadruplets. Their four delightful children have changed their lives and she describes the challenges they have overcome.

Let me introduce you to my family. I am the mother of four children who happen to have the same birthday. My husband, Ray, and I went from being DINKs (dual income, no kids) to a family of 6 in about 4 minutes. Yes, the children are quadruplets. Ben, Kirby, Colin, and Holly were born almost 3 months prematurely and weighed in at around 2.5 lbs each. My career has changed dramatically in the last 5 years and I now work around the clock for absolutely no wages but the benefit package cannot be surpassed. Life is not always a bed of roses, and I have never been so challenged, but I try to keep my family moving toward greater growth and independence.

Colin is the reason I am writing this article. He is a bright-eyed four-year-old with a winning smile. He has cerebral palsy and is non-verbal. He seems to have a good understanding of the world around him and is beginning to use switches for communication. He also has some sounds that we have attached meaning to and can be used in specific situations. It has been very challenging for us as parents, and for Colin, to get this far.

**"We were caught
in a vicious circle
of struggling to feed him
and keeping him
from vomiting."**

As an infant, he was very fussy and resistant to being out of our arms. Ray would often eat his dinner with Colin in a Snuggli sack on his chest and a napkin on Colin's head to keep the crumbs from falling on him. Colin was not a good sleeper. He would awaken several times during the night and it would take a considerable amount of time to settle him again. He needed to be picked up and carried around until he finally fell asleep and we would put him back to bed very carefully. Often, just laying him down on the bed would wake him again and we would start all over again. It has been a very recent step to finally put him to bed awake and have him fall asleep there in less than 20 minutes time with one of us at his bedside.

Colin's biggest challenge has always been, and still is, related to feeding. He has a significant degree of oral-motor dysfunction which

makes it difficult for him to coordinate sucking/sipping and swallowing. Feeding was always a very lengthy process and very stressful for both Colin and whoever was feeding him. In addition, Colin also has gastroesophageal reflux which causes him to vomit frequently. It was a constant battle to get enough nutrition into him and to keep it there.

Fortunately, with the help of medication, high quality nutritional products, various feeding techniques, and a lot of support and determination, we have made many improvements. Over the past year, Colin has gained over 12 lbs. (one-third of his body weight) and we have avoided the G-tube once again. It may still be in Colin's future, but for now, he remains totally orally fed. One of the great stumbling blocks has been his ability to tolerate seating. At first, much of the difficulty related to being out of our arms. We were caught in a vicious circle of struggling to feed him and keeping him from vomiting.

When he was put on the floor or in a chair, he would cry so hard it would cause him to vomit. So we held him. Then, of course, he liked that and needed to tell us how much he liked it so he cried when we put him down. Bit by bit over time we finally were able to have him sit in his chair to feed him. Holding him for feeding had become an impossibility due to his length and the strength of his little body. At times, it was like feeding a screaming "two-by-four". He now eats all of his meals in his chair, eats soft pureed foods and drinks thickened formula from a cup.

Colin's head control and vision limitations have made picture boards

and visual scanning a less than optimal method for augmentative technologies. Auditory scanning has become the method of choice for him. Colin currently has a computer and a Speak Easy, a basic voice output device, each with switch access. We tried to introduce Colin to using switches while trying to balance him on our lap and support him enough to be able to use his hands and try to hit the target. This was extremely difficult for us to do. We needed about 6 more hands!

Mealtime has presented us with the greatest opportunity for facilitating communication skills. At first, non-verbal cues of lip smacking and head control were all we had. Gradually, some sounds emerged in a consistent fashion (Colin had been a babbler since about one year of age). When Colin was able to tolerate a tray on his chair he was able to begin to use augmentative methods. He now uses 2 switches at mealtime in addition to his vocalization to tell us what his choices are.

I have found the process of augmentative communication to be a very frustrating one. When Colin was very young, we used toys attached to switches to facilitate his understanding of cause and effect. He gained this understanding fairly quickly. When it was time to move on to a voice output device, I then had to decide what Colin wanted to say in each different situation. It has always been my feeling that he had much to say and having total control over his words made me feel very uncomfortable.

My other children have taught me that what an adult chooses to say or do can be very different than what a child may choose to say or do. As Colin gets better at scanning, he is beginning to have a broader choice and we are getting better at follow-

ing his lead. Holly and Ben have been very fortunate that their development has followed the normal pathway. They are both very busy children with very different personalities. Holly is very motherly and loves to help with Colin. Her favourite things are colouring and Disney. Ben is the academic who likes to read and use the computer. Whenever anyone has a problem with a program, we call Ben to help. He is a very active boy who likes to be on the move. Kirby has cerebral palsy too. She is able to walk with a walker and do many of the things the other kids do. She is very verbal and lets her wishes be known in a very clear fashion. We always try to encourage her to do things for herself. Her determination to do things in her own way can be frustrating when trying to get 4 four-year-olds moving in the same direction and getting anywhere on time.

**“Having such an active
and verbal family
has been very fortunate
for Colin.”**

Kirby loves babies, babies, babies. She has quite a bizarre sense of humour (which she gets from her Dad). When she grows up, she wants to be a Big Lamp. Having such an active and verbal family has been very fortunate for Colin. He always has his age-appropriate peers around him to model behavior and language - both good and bad. He really enjoys the boisterous play and laughter. I am often asked if things are getting easier as the kids get older. The answer is “No, just different”.

Each of my children is unique in their personalities, skills and inter-

ests. Colin’s many needs relating to mobility and independence are quite time consuming and most often met in the home or on family outings. Kirby still has a very active therapy program following surgery last year and that keeps us busy with a lot of travelling. She wants to participate in just about anything and everything, and some things are just too difficult for her. Holly and Ben want to skate, swim, play T-ball, etc. A big challenge for us is to organize all of these activities and still make sure nobody is left “home alone”. Life is very different now compared to before we had our children. If I had a crystal ball then to see into my future, I would have been terrified. We have learned to live one day at a time with one eye on the future. We take great pride in the new accomplishments of each of our children, whether the steps are small or large. We do not lament about what might have been, we just try to raise all of our children to be happy, involved, and as independent as possible. Our calendar on the fridge is covered with notes and reminders of appointments and activities. Many people have asked me how we manage. My answer is always “With lots of help”. §

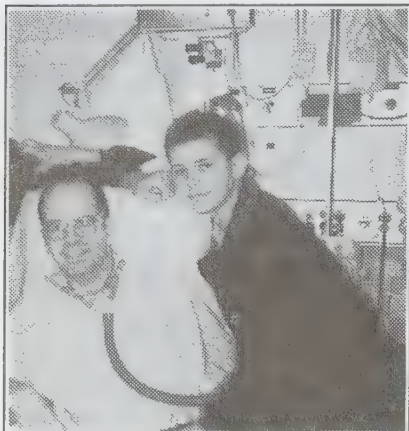
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How the Family Changes

BRIAN PAMPLIN



Brian Pamplin with his son Gregory

Since writing his article for the March issue of *Communicating Together*, Brian's life has undergone dramatic changes. The week prior to our spring Associate Editors' Annual Meeting, pneumonia added serious complications to Brian's life with multiple sclerosis. A tracheotomy was required and Brian had to move to the Intensive Care Unit of St. Joseph's Health Centre to receive the special care he needed. We all were greatly concerned for him and very disappointed that he could not participate in our Annual Meeting at Niagara-on-the-Lake. We knew how much he would have contributed to our discussion, and we also knew how much he had been looking forward to coming.

As the weeks went by, Brian moved from the Intensive Care Unit to the Acute Care Unit, and eventually to a regular hospital room, where we have worked together on this article. Brian has been thinking about what he wanted to say regarding family matters ever since he learned about the theme when he was in Acute Care.

As we began working on Brian's article, I could not refrain from contrasting our interaction in a quiet corner room of St. Joseph's with the outside surroundings. St. Joseph's Health Centre is located just to the north of Lake Ontario, with only the Lakeshore Highway, the Gardner Expressway and the "Go" Express railway tracks lying between the hospital and the waterfront. Cars and trucks are continuously rushing by on eight traffic lanes; at intervals, a train speeds along its track; boats, bicycles and pedestrians can be seen moving along the lakeshore. Movement and speed dominate the landscape that is visible from the hospital window. In contrast, for Brian and me, the pace is slow, with all our attention being focussed upon Brian's laborious sequencing of words. He has so much he wants to say and I can feel so inadequate as I work to interpret his full message!

Because of the tracheotomy and suction tube, Brian can no longer produce an audible sound. He puts much energy into forming the words for me to lip-read — but frequently I fail to identify the intended word. We augment the lip-reading with an ETRAN board, which Brian uses to spell full words and to give initial letter cues. Most of the time he indicates the letter location with a two-step eye gaze, but sometimes, in gentle frustration with me, he lifts a weak hand to directly point to the letter. Slowly — with countless questions on my part and many clarifications and new starts by Brian — we piece together his message for **Communicating Together**:

When I got MS, I told my wife to go and find a boyfriend, and she did. It is better for my son that she did. My son (eleven years of age) calls him "step dad". I am his "dad". That's how my son differentiates between us. I feel he has been a good influence on my son. If I can't be with Gregory, it is better that somebody else can.

It was important for me to think about and plan for my wife's future. I have been able to see that these changes are made in our family but I have not been able to share all my reasons and my feelings about these changes with my son and wife. This is where my communication limitations intensify the difficulties caused by my MS. My wife and son don't realize how much more I would like to say to them.

My family and a few others use the ETRAN when they can't understand my lips, but not many people have the time. The biggest thing is having people take the time.

I learned lots in writing "How the Family Changes" with Brian. As we talked together, and a caring nurse asked questions about our communication, the key factor of time was again reinforced. In the hour we had together before Brian became too tired for any further conversation, he was limited to so little expressive communication compared to we talkers! Brian and I used as many techniques as our lite technology afforded, but what he could say came down to how long his energy would last and how much time I, as his partner was able to give!

After meeting with Brian, I asked Kari Harrington and Nancy Gibbons for permission to print some of the words from their song, "Take the Time!" in **Communicating Together**. They happily agreed. We are all hoping delegates will hear the entire song at the upcoming ISAAC Biennial Conference in Vancouver in August. We have submitted a taped version of the song and await the planning committee's decision. Even if it cannot be included during a formal event, I hope to share the song at the Party following the Awards Banquet. It's a very beautiful reminder of the most important ingredient of successful AAC communication — Partners taking the time!

Take the Time!

Take the time
To look at me.
Take the time
To listen.

Take the time
To know me.
Take the time
To talk.

Take the time
To ask a question.
Take the time
For answers.

Take the time
To understand.
Take the time
To be a friend.

Brian and I both look forward to his continuing improvement and a return to his being able to use the computer to express his thoughts independently. We hope it will be in the very near future. We only wish that computer technology could be available to every hospital patient in the same way as intravenous, suctioning and monitoring systems! We wonder how many decades and how many government changes will be needed before patients confined to their beds in hospitals will have the wonders of current communication technology available to them — both for interpersonal communication and for travelling the electronic highway as readily as that fast-paced outside world!

§

Families and Parenting Through the Life Cycle: Planting Seeds

ALDA STEPRANS

In this article, Alda expresses feelings about families dealing with illness as she sees them as a nurse. Her insights are invaluable and show her genuine understanding.

Although we most often think of parents as the mothers and fathers of babies, children or perhaps even young adults, it is nevertheless true that this parental role persists throughout the lifecycle. Our roles as family members are constantly changing as our families grow and develop. Even in the most stereotypical family, life's circumstances require each family member to adapt to the changes that occur as children are born, start going to school, finish school and start working, move away from home, marry, and start new families. My role as a nurse has

provided me with the opportunity to meet many families at many different points in life. Each family's uniqueness, its way of evolving and being, is a source of fascination to me. Just as we must learn about each client's strengths and abilities in order to maximize a healthy lifestyle, so must we take into account the strengths and abilities of each family. But our nursing role does not end with simply helping the patient or family discover strengths. It often involves helping the entire family find the resources it needs to cope with changes in health, family roles and life styles.

Life is seldom stereotypical. Some of us are born with handicaps and disabilities, visible or invisible while others develop them through our lives. Death foreshadows each of us. Although some people are given warning of its imminence and can

prepare for it in some fashion, for many others death is unexpected. This wide range of potential challenges we may be faced with rules out the hope of any single solution to any family's problems.

What is usual amongst families is that its members care for and about each other. When there are problems in the family, its members interact to try and solve or minimize those problems. Sometimes it may seem that some family members don't care, but because each of us has our unique strengths and weaknesses, some of us may not know how to show that we care in a way that is accepted as normal. We may show caring in singular ways that others may find difficult to understand. We must remember that neglecting to visit a family member in hospital, is not necessarily an indication that the person is not cared about. Our role,

as nurses, must be to try to find ways to make the hospital environment conducive to caring from family members. How can we help family members understand the meaningfulness of their family roles, whether they are changed or not, and help them to fulfill the roles they can still play in their disabled mothers, fathers and children's lives? How can we help the handicapped, disabled, ill clients we care for understand their changing, evolving roles in their families? To what extent do they have the physical, emotional and economical resources to show their care? Can we help them strengthen these resources? It is vital that we take the time to communicate, listen, support, understand, and encourage.

Decreased skills in communication ability make the challenges of adapting to new roles even more difficult. It takes time to understand how someone who has lost the ability to communicate feels about life, about their role in their family. Psychologically, it takes time to accept the inability to talk as a part of one's self and surely it takes time for each family to understand the impact of this change on its way of life. Physically, it takes a great deal of time to understand and get to know somebody who cannot communicate verbally. Sometimes, it even takes time to feel comfortable, to accept the person who cannot communicate as a person. It takes time to learn someone's body language and cues. Time is, unfortunately, one commodity that often does not fit into many people's lifestyles. It is often helpful for family members coming to visit a relative who can no longer speak, if staff help to build some time bridges,

help the family understand what cues to watch for, help them to try to understand what they may mean. Staff, of course, often learn from relatives what some of the body language cues may mean.

“Our role must be to try to find ways to make the hospital environment conducive to caring from family members...”

It does not take long to empower family members, to show them how to help and care for their loved ones.

Sometimes in our rush to finish all that work we have to get done, nurses forget to stop and take those few minutes a family may need to point out the importance of visits, even if they are infrequent. They are not insignificant in helping to understand the client's role as a family member. That role may be changed, but it is certainly not irrelevant. It does not take long to empower family members, to show them how to help and care for their loved ones, even by such simple actions as bringing in something special to eat or drink, by propping up a pillow, by holding a hand. Sometimes, with their heavy work loads, hospital staff do feel tired. It may sometimes seem that family members are interfering, taking up too much of the energy which staff feel they should be giving to the clients, but by helping clients maintain a place in their families, staff are also caring for their psychosocial needs. Taking that

initial time, to understand each family member's problems and strengths, involving these people in the active care of their family members may decrease feelings of helplessness and guilt and help them understand their vital roles in their family.

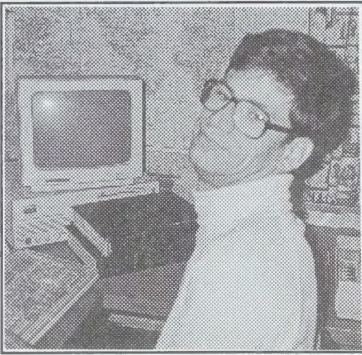
Finally, as a nurse I must mention one more area where family plays an undeniably important role and that is in advocacy. Our health care system is one of the best in the world, partly because so many people have advocated on behalf of family members for more humane care. Of course, these changes have also occurred because health care professionals have been willing and able to listen to what family members feel is important. Sometimes modifications seem to take much too long and come much too late for those we care about. It's a fact that transitions often take time. True, meaningful changes often require an alteration in understanding that just can't happen overnight, but let's not be afraid to share our views, to stand up for the rights of those we care for, to try to understand each other and search for solutions together. Even if our suggestions are not listened to rightaway, the seeds of thinking we have planted just may at some point in the future take root and sprout.

These changes have also occurred because health care professionals have been willing and able to listen to what family members feel is important.

§

Sharing Parenting

PAUL MARSHALL



Paul Marshall

Let me welcome you to another article from Paul's desk. In this issue we are thinking about what it means to be a family and about parenting. In my mind there is no greater privilege in life than raising our future generation. When we think of the family unit, it is so natural to think about the biological family, but for this article I would like for us to think about parenting on a global level.

There is no doubt, the biological family unit plays a major role in early development of our children. Research tells us that the early years are the most critical. I so often reflect on my own childhood and am very thankful that I had a good family unit and a greater family that was made up of grandmothers, grandfathers, aunts, uncles, cousins and many significant people that played a vital role in my development. It is so easy for us to believe that it is the environment, positive or negative, that makes the difference in a person's life. As much as our environment plays a part in one's existence, it is the family or the

people that we come in contact with which impacts greatly in development. I could reflect on the farm environment which I was blessed to grow up in and put greater importance on it, than the impact that countless people have made upon my life. There is no question in my mind my farm environment gave me the physical strength to allow me to improve myself, but it was my family and people around me who nurtured the inner person. It is the people in our lives that make the environment positive or negative.

When we discussed doing this issue on Family and Parenting, the first thought that came to me was to ask my eight-year-old nephew what and how he saw me as a disabled person. When my sister-in-law asked Nicholas this question, he stopped for a minute and then wrote this: "When mom asked me to write about what I thought of Uncle Paul being disabled, I said 'I forgot he was disabled. Uncle Paul teaches me so much and he is a great uncle. I'm proud of him.' When I read this, tears came to my eyes. *Nicholas, I hope you will always be capable of overlooking people's and society's many outer disabilities.* Nicholas along with my two other nephews and one niece have been brought up around me and they see me as just their uncle Paul, not uncle Paul who is disabled. I can remember when I was going to school on Mom's school bus, friends would go home and tell their parents that Paul said this or that. When they saw my mom and found out that I was nonspeaking, they were taken aback.

We are all parents - mothers and fathers or ones who influence others. Our lives and our lifestyles are not private. We are living in a time where there is great pressure being

put on the family unit. It is a time of unrest and many people are not at peace with their circumstances. Just the other day I was talking to one of our neighbours, who is working in the construction field. He was saying he is now working with men whom he knows used to take great pride in their work and in a job well done. Now they now don't care and are just throwing their work together, and bad mouthing anybody and everybody who is in charge. We wonder why many youth of today are taking drugs, are not willing to submit to anybody, and who don't take pride in who they are. When adults model and live very badly, how can we expect to raise a generation who will take pride and have self-worth? What and how we live, speaks volumes. I personally believe what is wrong with youth today is us — the global society.

When we talk about any AAC user/consumer and their family and their society, it is the same. What are we modelling and why are we modelling this type of behaviour? Are we modelling that if you have any kind of disability, that gives you the right to expect that the world owes you everything. Or are we modelling that the heartbeat of peace and happiness can give an inner being the strength that will radically make an impact on our world? I hope my impact upon my nephews and niece will help and guide them to be healthy and upstanding individuals. After all, I am their uncle but most of all I am a person who is blessed to have a responsibility in their lives.

We are all global parents and our job is guiding, modelling and helping others. Let's do the best job that we can as global parents.

See you next time.

§

We Are Family

MICHAEL WILLIAMS

*Michael Williams, editor of **Alternatively Speaking**, is a long time contributor to the field of **Augmentative and Alternative Communication**. We welcome his perspective as a parent who happens to use AAC. His wit and keen insights are always appreciated.*

"Shut up and take your son!" came the words from high atop the delivery table. I could hear my wife Carole's exhausted voice roaring in my ears. It was her endearing way of telling me not to be afraid of the small human who was being presented to me by a nurse. Malcolm — that's my son's name — fit perfectly in my arms. He was the first baby I ever held: I was forty-seven years old and it was a miracle. I know that's a cliché, but this event was truly miraculous. In fact, had you placed a bet the day I was born on the chances of such an event occurring, you'd now be wealthy enough to pay off the national debt.

By all odds I should have died at birth. But I was stubborn and decided to live. By all odds I should be spending my life in a state institution. But I was stubborn and decided to take my place in the real world. By all odds I should be a lonely bachelor. But I was stubborn and now find myself living with my wife of fifteen years and our two children, Malcolm, who is eight years old, and Ellen, who is still working on her first year.

"Malcolm is very popular amongst his peers, although they find us a very curious family indeed."

Parenting is never an easy job. Kids don't come with owner's manuals or easy care instructions. There is no parenting university, and even if there were, half the things learned wouldn't be applicable to any practical situation. But there is one absolute of parenting: Everybody's an expert on the subject, and people feel free to share their copious knowledge with you at the drop of a diaper.

This is especially true when you use a wheelchair. When Malcolm was a newborn, people would literally chase us through streets, department stores and other public places to correct our childcare techniques. These complaints mainly centered around supporting Malcolm's head.

"Hold that kid's head up," they would yell. "He's looking at all the bright lights; he's fascinated by them," my wife would reply. No matter. They still kept complaining. Things got so bad that our pediatrician gave us a stack of her business cards to pass out to all kibitzers. We would tell them to present any complaints to her. She would assure our critics that Malcolm was well loved and well cared for.

Carole and I soon discovered we needed a lot of patience and creativity to parent effectively. We have

physical skills that complement each other. I can twist lids off jars without working up a lather, but it hurts Carole's hands to open jars with tightly screwed on lids. I can't lift my children, and Carole isn't supposed to carry heavy objects for long distances; so like she did with Malcolm, Carole lifts Ellen onto my lap, and I carry our daughter as we do our errands around town.

Our children have done their share of adapting, too. Carole's mother complained the other day that Ellen doesn't pull herself up on people's fingers when they are offered to her. We considered this puzzling fact awhile and then discovered the reason for it. Since Carole must protect her fingers from being squeezed or pinched, she never extends them to Ellen. Carole uses her forearms to pick up Ellen under her arms. It took Ellen about a month to realize this; now she puts her arms straight out so that Carole has an easier time picking her up.

When Malcolm was a toddler we taught him to climb up on the footrests of my wheelchair so I could take him for walks in the neighborhood. Since I use a power wheelchair, it was important to teach Malcolm never to grab my joystick. I was doing a great job of saying, "No!" in a loud gruff voice and shooing Malcolm's hand away from the inviting control stick, but one day it happened: Malcolm grabbed the joystick and we went full speed into a wall. We were both scared but uninjured, and Malcolm learned a valuable lesson: Malcolm rides. Daddy drives!

As Malcolm has grown, he has become a full-blown jock, much to Carole's surprise and, I suspect, chagrin. The woman who knew nothing about sports until I married her, now serves as her son's hitting and pitching coach thanks to instructional videotapes and her keen analytical mind.

Malcolm's fascination with the sporting life has brought us into an element of society we otherwise would have no entrée into. A lot of the families of kids in organized sports are from a very different economic and social stratum than ours. While Malcolm and Ellen never lack for life's basics, some of these children have more access to the more interesting baubles of

childhood. This has sparked some very spirited discussions with Malcolm about the nature of economic and social justice. We trust our presence at games has sparked similar discussions in his team mates' families.

Malcolm is very popular amongst his peers, although they find us a very curious family indeed. Of course they are interested in my wheelchair, my unclear speech and my speech synthesizer, but they become even more animated and questioning when they discover that Malcolm isn't allowed to play with guns or Nintendo video games, or watch hit movies like Terminator Two or Jurassic Park.

Some people think that ours is a most unusual and unique family. It is not. We want for Ellen and Malcolm

what every parent wants for their children. We want them to grow up with self-confidence together with a strong moral, ethical and spiritual framework that allows them to have understanding and compassion for people who are different from them.

This article was originally published in Parenting for Peace & Justice Network, Newsletter Issue Number 59, October, 1993, published six times a year by The Institute for Peace and Justice, St. Louis, MO, USA. We thank PPJN for their permission to reprint Michael's article in Communicating Together. §

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Communicating Together, established in 1982, is published quarterly since 1991 by *Sharing to Learn*. Its mandate is to provide a means of sharing the life experiences and communication systems of augmentative communicators with other augmentative communicators, their families, their communities and those who work with them.

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Typesetting & Printing: Central Printing Services, Guelph, Ontario.

Subscription Rates per Year:

Canadian - \$25.00 Cdn;
U.S. - \$23.00 U.S.;
Outside North America - \$30.00 Cdn.

ISAAC Members' Rates

Canadian - \$20.00 Cdn
U.S. - \$17.00 U.S.
Outside North America - \$26.00 Cdn.

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Second Class Mail Registration No.7093
GST Registration No. R130220619
ISSN No. 822-0638

Cover: The cover picture was drawn by Candyce Dube, when asked to make a picture of her family. Candyce's thoughts about her relationship with brother, Jordan, appear on page 5 in our feature article, "Your Brother has CP?! So Does Mine!".

The publisher offers **Communicating Together** as a vehicle for editors, associate editors and contributing authors to present their perspectives on augmentative and alternative communication. The views expressed are not necessarily those of the publisher although the human interest, consumer involvement and international perspective are.

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Communicating Together is an affiliated publication of the International Society for Augmentative and Alternative Communication (ISAAC).